

A web project of Kennedy Krieger Institute  
Sponsored by Autism Speaks



share

research



discover

Linking the autism community and researchers



What causes  
**autism?**

How do  
**genetics**  
and environmental  
exposures impact  
**causation?**





Which **autism**  
**treatments**  
work best?

What evidence  
supports the use  
of this **treatment**?



# We all have questions. **Together we'll find the answers.**



## What is the Interactive Autism Network?

### Accelerating the pace of autism research

Every day, researchers from around the world are seeking answers to questions about autism spectrum disorders (ASD), and looking for insight into causes, the most effective treatments, and family burdens and challenges. And when one in every 150 children will receive a diagnosis of autism each year, the need for research to move ahead is urgent.

Yet hundreds of research projects are put on hold because researchers simply do not have enough qualified participants to gather the information they need to make progress in their studies.

And while there are an estimated 1 to 1.5 million people in the United States living with ASD, fewer than 10 percent of them participate in research studies. By comparison, 94 percent of all children younger than age 15 diagnosed with cancer are enrolled in research, which has lead to remarkable advances and many proven treatments.

Since 2007, the Interactive Autism Network (IAN) has brought together tens of thousands of people affected by ASD and hundreds of researchers from around the world in a search for answers about this puzzling group of disorders.

Individuals of all ages with ASD and their families contribute the vital information only they possess: knowledge about their diagnoses, treatments, services, and life challenges. This dynamic exchange has enabled researchers to access this invaluable data and gain new insights, while also matching interested participants with local and national research projects for which they qualify. These efforts have already advanced over 150 research studies from respected organizations, including the National Institutes of Health, Harvard University, Stanford University, and Yale University.

In addition, the data collected by IAN has empowered community leaders to advocate for improved services and resources and has helped shape public policy.

Families, researchers, and anyone impacted by ASD can also access IAN's comprehensive online library and meeting place which focuses on ASD research. Visitors learn about the latest research, become more informed consumers of research, and join a worldwide collaboration of people dedicated to finding answers.

Join the nation's largest online autism research effort and become part of the solution. Visit **IANproject.org**.

**“Every child is different. And unless we as parents tell the researchers what is specific to our child – how will they know? They don't live with the children, they don't see them every day.”**

—IAN participant

## IAN Research

### Linking autism researchers and families

IAN Research gives you the opportunity to make important contributions to research from the comfort of home, as your schedule allows.

You will answer questions on a variety of topics including:

- Diagnosis
- Development
- Family history
- Services received
- Treatments
- Economic burden and family stress

Periodically, as new research topics are explored, you will have the opportunity to complete additional questionnaires.

The information you share helps researchers throughout the world make advances in the understanding and treatment of autism. In addition, IAN research data provides crucial information to policymakers whose decisions impact the lives of people on the autism spectrum.

IAN Research also serves as a research registry, matching interested participants with research projects for which they qualify.

*Please note that information is shared with qualified researchers without disclosing the participants' identities.*

### Who can participate?

1. All children under the age of 18 in the United States who have been diagnosed with an ASD by a professional are eligible to participate. The child must be enrolled in IAN Research by a biological or an adoptive parent who is legally authorized to provide consent. Once a research profile is created, other eligible family members may participate, including other biological/adoptive parents and any full or half-siblings (under the age of 18).

2. All adults in the United States who have been diagnosed with an ASD by a professional are eligible to participate. Adults with an ASD who are able to provide consent for themselves may create their own research profile and then add additional eligible



family members, including any biological/adoptive children (under the age of 18) and any other parents of these children.

3. Adults with an ASD who are not able to provide consent must be enrolled in IAN Research by a legally authorized representative (such as a guardian). Once a research profile is created, other eligible family members may participate, including biological and/or adoptive parents of the individual with an ASD.

ASD diagnoses that are included in IAN Research:

- Autism or Autistic Disorder
- Asperger Syndrome
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- Pervasive Developmental Disorder (PDD)
- Autism Spectrum Disorder (ASD)

To join the nation's largest online autism research effort visit **IANproject.org**.

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## IAN Community

### Linking the autism community and researchers

The latest research reports. Articles from leaders in the field. A wealth of unbiased information. These are just a few of the things that IAN Community, a comprehensive online library and meeting place focused solely on ASD research, has to offer. It's bringing the best and most up-to-date information on ASD together in one place for you.

When you become part of IAN Community, you'll:

- Read articles about diverse research topics – from genetics to education – written by leading researchers in the ASD field.
- Explore IAN Research Reports to find out the results of our online research questionnaires.
- Ask your questions on our forums and get answers from others living with ASD.
- Influence the direction of future autism research.

- Gain a better understanding of the research process.
- Understand the impact your participation can have on autism research.
- Learn how the Interactive Autism Network is helping change public policies to improve the lives of children and adults with ASD.

### Who can participate?

Anyone who is interested in ASD can participate in IAN Community. It brings families, friends, and individuals with ASD together with researchers, educators, therapists, and other autism professionals to better understand these complex disorders.

To find out what tens of thousands of people are telling us about autism, visit IAN Community at **IANproject.org**.



# The Interactive Autism Network is Already Making a Difference for...



## Researchers

"It has already yielded such significant benefits not only to families, but to researchers and policymakers." —*Researcher using IAN data*



## Families

"Doing this [participating in IAN Research] made me feel I was doing something to help us get closer to finding a positive solution."

—*IAN participant*



## Advocates

"As an advocate for people with autism and their families, I need current and reliable information on the autism community's experiences. IAN gives me that information. It's a great tool for working with federal and state policymakers."

—*Stuart Spielman*

## Key Accomplishments

- More than **150 research studies** have used data from or recruited participants through IAN, in some cases allowing previously stalled studies to move forward.
- Scientific advancements were published in key **academic journals** including:
  - *Journal of Autism and Developmental Disorders*
  - *Proceedings of the National Academy of Sciences*
  - *Archives of Pediatrics & Adolescent Medicine*
- Advocates are using IAN data to help influence **public policy** on critical issues such as insurance coverage for autism treatments.



To make a donation to help advance  
autism research visit

**donate.IANproject.org**

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**AUTISM SPEAKS™**  
It's time to listen.